

**One year mortality after hospital admission as an indicator of palliative care need in the Western Cape, South Africa: an incident cohort study.**

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# Table of Contents

List of tables and figures.....	3
Declaration.....	4
Acknowledgements and contributions.....	5
Abstract.....	6
Background.....	6
Aim.....	6
Design.....	6
Setting.....	6
results.....	6
conclusion.....	6
Introduction and literature review.....	7
Intention.....	8
Search strategy.....	8
The need for palliative care and defining a population.....	8
Scope of palliative care.....	9
Estimating palliative care need.....	10
Using death certificate data.....	10
Using data linkage of hospital records and mortality records.....	11
Other models.....	12
Survey based.....	12
Palliative care and the world.....	13
Studies specific to palliative care need in Africa.....	13
Studies done in the South Africa.....	14
Studies done in the Western Cape province of South Africa.....	14
References.....	16
Publication ready manuscript.....	19
Authors and affiliations.....	20
Abstract.....	21
Background.....	23
Participants and Methods.....	24
Data Sources.....	25
Study design.....	25
Results.....	26
Discussion.....	27
Conclusion.....	28
References.....	30
Table 1.....	32
Figure 1.....	33
Declarations and authorship.....	34
Appendix.....	35
Ethics Approval.....	36

# List of tables and figures

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Table 1: Characteristics of the patient cohort and mortality rates .....	32
figure 1: Cumulative deaths as a percentage of admissions by age .....	33

**Declaration:**

I, Petronella Frankenfeld, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Date: 22/11/19

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## Abstract:

**Background:** Globally there is an increasing awareness of the need for end-of-life care and palliative care in hospitalized patients that are in their final year of life. However, limited data are available in low and middle income countries which hinders the design and implementation of effective policies and health services for this patient group.

**Aim:** To determine the proportion of patients who die within one year from their date of admission to hospital in public hospitals in South Africa.

**Design:** Retrospective incident cohort study using record linkage of admission and mortality data.

**Setting:** 46 acute care public hospitals in the Western Cape Province of South Africa.

**Results:** Of the 10 761 patients (median age 44 years; IQR: 31 - 60) admitted to 46 hospitals over a 2 week period in March 2012, 1570 (14.6%) died within one year, the majority of the deaths occurring within the first 3 months. Mortality rose steeply with age as expected. The median age of death was 57.5 years; IQR: 45 - 70. A greater proportion of patients admitted to medical beds died in one year (21.3%) as compared with surgical beds (7.7%).

**Conclusion:** Despite a median age under 60 years at admission, a large percentage of patients admitted to public sector hospitals in South Africa, an upper-middle income country with a high HIV and non-communicable disease burden, are in the final year of their lives. This finding highlights the need for planning and implementation of end-of-life and palliative care strategies for hospitals and patients.

(word count = 250)

## **Introduction and literature review:**



**Intention of this literature review:**

Reviewing the available published data on Palliative care need and defining a palliative care population across the world in relation to hospital admission.

To look at specifically what data is available for African countries and focusing on what has been done in Southern Africa to advise on the development of palliative care services according to need.

**Search Strategy:**

A structured search was conducted on electronic databases: PubMed, Scopus and Google Scholar for relevant literature.

Only English and full text articles were included.

Literature was reviewed up until the beginning of 2019.

Literature was also searched for manually after screening the references of identified studies during the electronic search.

The following key words were used:

Palliative care need

Hospitalization

Mortality

Death

Data linkage

Palliative care Africa

**The need for Palliative care and defining a population:**

Globally, a growing need exists for providing appropriate end-of-life care at population level. Approximately fifty-eight million people die annually; forty-five million of these deaths are in developing countries. It is estimated that 60% of these people will have a prolonged advanced illness and could benefit from end-of-life care interventions, including palliative care.(1) As the ageing population world wide is growing, it is reasonable to deduce that the population with chronic progressive diseases in need of palliative care will also increase over time.(2)

Palliative care can be defined as an approach that improves the quality of life and provides relief from pain and suffering for patients and their families facing incurable, life-limiting disease. This holistic, patient-centered approach focuses not only on biomedical care, but also on psychosocial and emotional support. (1) Palliative care is focused on symptom control of not only pain, but other symptoms as well. It regards dying as natural and does not intend to either postpone, nor to hasten death.(3) End-of-life care is defined as: “a population based approach which helps all people with advanced, progressive and incurable illness live as well as possible until they die. It enables both supportive and palliative care needs of the patient and family to be identified and met throughout the last phase of life and into bereavement. It includes the management of pain and other symptoms and provision of psychological, social, spiritual and practical support.”(4) An integrated care pathway for end-of-life care in the United Kingdom includes the following: Care for physical symptoms, psychological and spiritual support, improved communication between family members and also with primary care team and planning for bereavement.(3)

#### Scope of palliative care:

Palliative care is aimed at all patients with life-limiting illnesses not only malignant, but also chronic diseases. Awareness of this has increased over the past two to three decades, however the majority of patients accessing palliative care still have a diagnosis of cancer.(3) Non-cancer illnesses have varying patterns of progression and some follow the expected route for life limiting illnesses with slow progression to death, others could abruptly end in death and some may require intermittent palliative approaches as there are periods of improvement interspersed between periods of progression of disease during which palliative needs arise.(3) Traditionally palliative care was mostly associated with malignant cancers, however, many non-cancer conditions have also been identified as needing palliative care during the course of the illness and nearing demise of the patient. These conditions include end stage organ failures: renal, liver, cardiac and chronic obstructive pulmonary disease. Neurological conditions such as stroke, multiple sclerosis, Alzheimers, Parkinson’s disease, Huntington’s disease and Motor Neurone disease are also well recognized as needing a palliative approach. Communicable diseases like HIV/AIDS have also been

recognised as potentially benefitting from palliative care and has been included in estimates of a palliative care population when looking at death certificate data.(5, 6) The Cleveland Clinic foundation found that with patients who are referred to palliative care services were referred quite late in their diseases, especially when they had a diagnosis other than cancer. Of the patients referred to them almost 80 percent had cancer as the primary diagnosis and the rest had advanced non-malignant diseases. During the 3 months of the study 76% of patients had died and the median survival was only 62 days. (7)

#### Estimating palliative care need:

In order to guide health service planning, it is required to understand the level of need for palliative care at population level. The population need for palliative care has been estimated in several high-income countries using different approaches and methods. Mainstay approaches for assessing palliative care need include prospective predictive assessments based on patient diagnosis and assessment or retrospective analysis of one-year post admission death registry data.(8, 9) Several tools have been developed to try and define a palliative care population through a variety of methods. It has therefore been difficult to compare different studies as there is inherent variability in strategies pursued to define the potential palliative care population.(10, 11)

#### *Using death certificate related data:*

One method to decide on need of palliative care is to use death certificate related data and exclude the people who had trauma related or sudden unexpected death, the remainder may have derived benefit from palliative care leading up to their death.(11) There has been some improvement on this method by using pre-selected causes of death from well known chronic conditions likely to benefit from palliative care. (11) Other studies have linked this to admission to hospital and combining the death certificate and hospital admission data. (11, 12) These studies have been conducted in several countries and data is now available from United Kingdom , New Zealand, Australia, Denmark, Finland, Korea, France, Israel, Canada and the United States of America. (11) A study comparing these different methods found a disparity from 44% by using the underlying cause of death only. If secondary cause of death is included this increases to 63% and by adding hospital admission data this increased to 73% of patients who died who may have benefitted from palliative care. This means that using

the cause of death alone will likely underestimate the size of a given palliative care population.(10)

*Using data linkage of hospital records and mortality records:*

Defining a patient population requiring palliative care, in its broadest sense and in keeping with the philosophy of caring and should ideally be determined using a needs based approach. McNamarra et al used a population based approach in estimating palliative care needs in Western Australia using data linkages and death records and suggested using an estimation method and dividing the population into minimal, mid-range and maximal estimates of a palliative care need.(6) In a prevalent cohort study, using data linking between hospital admission and death records, conducted in Scotland in 2010, 12 month mortality was found to be 28.8% after hospital admission, at 3 months the mortality was already 16.0%. Of these deaths, 32.3% had already occurred during the index admission. This study was conducted on a specific date in 25 Scottish hospitals. Mortality rose with increasing age, male gender and medical rather than surgical specialty admissions.(13) In 2013 the authors repeated the same study, again on a single date and a similar results were obtained.(14) Murtagh et al described a modified system of reporting a minimum estimate of palliative care need. They conducted a study looking at all deaths in England over a 3 year period ending in December 2008 using mortality data and also linked hospital episode data. In this study it was estimated that a minimum of 63% of people who die will require palliative care before death. The minimum to maximum range extended from 69 – 82% of all deaths. Their conclusion is that using death data, including contributory cause of death, it will be possible to gauge a population estimate of need for palliative care even without hospital admission data.(12)

Appropriate end-of-life care is needed at hospital level as many patients die during hospital stay and a large proportion of those admitted to hospital are potentially in their final year of life. A hospitalization event also provides an opportunity for palliative needs to be identified and plans put in place at discharge to ensure good care in the community thereafter.(13)

*Using other models:*

A rural hospital in Ireland did a study to predict mortality one year after admission to hospital looking at a simple clinical score and electrocardiogram (ECG) dispersion mapping as predictive factors. At follow-up of 430 patients who were admitted to the acute medical service, it was found that 16.3% had died. ECG dispersion mapping combined with advanced age and a high Simple clinical score can be used to predict long term mortality outcomes on admission to hospital. (15)

Van Walraven et al developed a risk screening tool to predict one year mortality at hospital discharge. The initial study was done in Ontario in 2011 and found a one year mortality of 11.7%. (16) Hospital One-year Mortality Risk (HOMR) model was validated by Van Walveren et al to predict how many patients would die within a year of hospital admission using patient characteristic data captured on admission in Ontario, Alberta and Boston. This data was linked to death data and they found that the tool gave a reasonable prediction of one year mortality. The actual one year mortality found was on average 8.7% after hospital admission. (17) A follow-up study was done with an adjustment to the prediction tool to make it applicable for data captured at hospital admission. The HOMR NOW! Model was used in a single hospital and found good correlation with actual one year mortality data of 15.6% in the study population of that hospital from 2004 – 2014. (18) Recently Machine learning has also been used to predict one year mortality and palliative care need for patients on admission to hospital from electronic records with an automatic activation of the palliative care team to consult. (19)

*Survey based estimates of palliative care need:*

In Germany a study was conducted to try and find the proportion of hospital patients who need palliative care by asking the treating clinician if they felt the patient required palliative care. The clinicians identified 6.9% of patients who had palliative care needs. (2) In Sheffield in the United Kingdom, an interview based study including both doctors and nursing staff opinions regarding palliative care need estimated that 23% of patients admitted to an acute care hospital had palliative care requirements. 11% of the inpatients during the study period were identified by doctors and or nurses to qualify for admission to a dedicated palliative care bed. There was only about 9% overlap in patients who were identified by doctors and nurses to have palliative care requirements, however, as the predicted time of death came nearer, there was better

correlation between the opinions of medical and nursing staff. (20) In Belgium, 14 hospitals were selected for a study where interviews were conducted with medical and nursing staff. 9.4% of inpatients were identified as palliative by the staff interviewed. This was true for 13 of the hospitals in the study, but one hospital was an outlier with more patients fitting the category of palliative patients, likely due to the large amount of palliative beds in the specific hospital.(12, 21) In one New Zealand hospital a prospective survey of adult patients was done using the Gold Standard Framework tool modified for the New Zealand setting. This study found that 19.8% of adult inpatients met Gold Standards framework criteria and therefore needed palliative care, 33% of them died within half a year of their admission. (22)

#### Palliative care and the world:

Data from high income countries estimate that 69-82% of people at the end of life would benefit from receiving palliative care.(12) It has been found that around three quarters of deaths are caused by chronic and progressive diseases. These patients may have palliative care needs in the time leading up to their deaths.(12, 23, 24)

#### Studies specific to palliative care need in Africa:

There remains a dearth of evidence on population-based estimates of palliative care need in the sub-Saharan African health context, thus hindering the effective development of service provision.(25) A multi-country study conducted in Tanzania, Botswana, Ethiopia, Uganda and Zimbabwe found that at least 0.5% of total population requires palliative care.(26)

Roughly half a million people in sub-Saharan Africa die of cancer every year. This is probably an underestimation of the burden of disease if the difficulties in gaining access to healthcare in parts of Africa are taken into account. By the time most of the cancers are detected, they are advanced and incurable making a palliative approach reasonable. Due to the confounding factors of late presentation and limited resources, a lot of the cancers that are curable in developed countries are potentially not curable in parts of Africa. (27)

#### Studies done in South Africa:

End-of-life care is appropriate for all people with a chronic progressive incurable illness therefore the South African annual causes of death may further indicate the need for end-of-life care. Between 2011 and 2013 the leading cause of death in South Africa was infectious and parasitic diseases ~ 22% followed by circulatory diseases ~ 16%. (28). Within South Africa there is no clear nationwide data on palliative care need. Using only mortality data it is estimated that 49.7% of people dying in South Africa would have derived benefit from palliative care.(29, 30) There is however currently a strong National and Provincial drive for palliative care in South Africa. The National Health Council of South Africa has approved a National health policy for palliative care.(29) Recent mortality statistics describe the annual deaths from 2016 of 456,612. Of these, the age group 65-69 years had the highest percentage of deaths at 7.8%. The leading causes of death for 2016 were attributed both to circulatory disorders (18.5%) and Infectious diseases (18.2%), which demonstrates the dual burden of disease South Africa is experiencing.(31)

Of increasing significance is the role of the hospital in meeting the supportive and palliative needs of patients in the final stage of life. In South Africa, the highest proportion of deaths 43.2% occur in hospital.(31)

#### Studies specifically done in the Western Cape province of South Africa:

To date, there are only two published studies which have tried to determine the prevalence of palliative care need in acute care hospitals the South African context. A prospective point-prevalence study, using a contextualised Gold Standards Predictive tool, conducted in 2011 of 10 hospitals in the Cape Town Metro found a 16.6% prevalence of palliative care need amongst hospital in-patients. Most of these patients were in the general medical wards – 54.8% Half of them had a malignancy, followed by organ failures of which most were end stage renal failure. HIV and TB, perhaps surprisingly, accounted for only 9.6% of the patients identified to have a life limiting disease. (32) A second study, retrospectively reviewing mortality data from a tertiary hospital general medicine service in the Western Cape, determined mortality to be 11% at 3-months post discharge and 42% at 12-months post discharge.(33) To expand on the evidence base for prevalence for palliative care need in South Africa, a more extensive study is required.

Aim:

- To provide additional evidence of palliative care need for hospitalised patients in the Western Cape of South Africa

Objectives:

- We intend to use data-linkage with hospital admission and mortality data in the Western Cape province of South Africa to determine what proportion of patients who are admitted to acute care hospitals are in the final year of their life and would thus potentially benefit from timely initiation of palliative care services and interventions.

(word count: 2584)



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# **One year mortality after hospital admission as an indicator of palliative care need, an incident cohort study.**

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## **Abstract**

**Background:** Globally there is an increasing awareness of the need for end-of-life care and palliative care in hospitalised patients that are in their final year of life. However, limited data are available in low and middle income countries which hinders the design and implementation of effective policies and health services for this patient group.

**Aim:** To determine the proportion of patients who die within one year from their date of admission to hospital in public hospitals in South Africa.

**Design:** Retrospective incident cohort study using record linkage of admission and mortality data.

**Setting:** 46 acute care public hospitals in the Western Cape Province of South Africa.

**Results:** Of the 10 761 patients (median age 44 years; IQR: 31 - 60) admitted to 46 hospitals over a 2 week period in March 2012, 1570 (14.6%) died within one year, the majority of the deaths occurring within the first 3 months. Mortality rose steeply with age as expected. The median age of death was 57.5 years; IQR: 45 - 70. A greater proportion of patients admitted to medical beds died in one year (21.3%) as compared with surgical beds (7.7%).

**Conclusion:** Despite a median age under 60 years at admission, a large percentage of patients admitted to public sector hospitals in South Africa, an upper-middle income country with a high HIV and non-communicable disease burden, are in the final year of their lives. This finding highlights the need for planning and implementation of end-of-life and palliative care strategies for hospitals and patients.

## **Keywords**

Palliative care, terminal care, end-of-life care, mortality, inpatients, hospitalization

**What is already known about this topic?**

- There is evidence about the difficulty of identifying patients in the last year of their life and of transitioning to palliative care for hospitalized patients.
- A small point prevalence study in Cape Town metro has established the proportion of patients that might benefit from palliative care.
- Data from other countries have suggested that a high proportion of patients who are hospitalized are in the final year of life.

**What does this paper add?**

- This is the first study amongst a large undifferentiated cohort of hospital inpatients from an African country and one of the few in the world, using record linkage data that establishes the proportion of patients admitted who die in the following year.
- The study shows that a large proportion (14.6%) of patients will die, in spite of a young median age of admission.

**Implications for practice/theory/policy**

- The proportion of admitted patients who die within a year is comparable to developed countries; however patients are much younger.
- Admission to hospital may provide an opportune time to screen for and then initiate palliative management for patients.
- The culture and organization of hospitals and resource allocation needs to change and take cognizance of the large number of patients that will require end-of-life care.

## **BACKGROUND**

Palliative care can be defined as an approach that improves the quality of life and provides relief of pain and suffering for patients and their families facing incurable life-limiting disease. This holistic patient-centred approach focuses not only on biomedical care, but also on psychosocial and emotional support.<sup>1</sup> Globally, a growing need exists to provide appropriate palliative care at population level as approximately 58-million people die annually, 45-million of which are in low-and middle-income countries.<sup>2</sup> Data from high income countries estimate that 69-82% of people at the end-of-life will benefit from palliative care.<sup>3</sup>

In order to guide health service planning, it is required to understand the level of need for palliative care at population level. The population need for palliative care has been estimated in several high-income countries, using different approaches and methods.<sup>4</sup> Mainstay approaches for assessing palliative care need include prospective predictive assessments based on patient diagnosis and assessment or retrospective analysis of one-year post admission death registry data.<sup>4,5</sup>

There remains a dearth of evidence on population-based estimates of palliative care need in the sub-Saharan African health context, thus hindering the effective development of service provision.<sup>6</sup> A multi-country study conducted in Tanzania, Botswana, Ethiopia, Uganda and Zimbabwe found that at least 0.5% of total population requires palliative care.<sup>7</sup> Within South Africa there is no national data on palliative care need. Recent death statistics from South Africa, describe annual deaths (2016) of 456,612. Of these, the highest percentage of deaths (7,8%) occurred in the age group 65-69 years. South Africa has a dual burden of disease. The leading cause of death in 2016 was attributed to both circulatory disorders (18.5%) and infectious diseases (18.2%).<sup>8</sup> There is however currently a strong National and Provincial drive for palliative care in South Africa. The National Health Council of South Africa has approved a National health policy for palliative care.<sup>9, 10</sup> Using only mortality data it is estimated that 49.7% of people dying in South Africa would have derived benefit from palliative care.<sup>9</sup>



The role of hospitals and institutions in meeting the palliative care need of patients in South Africa are significant as 43.2% of deaths occur in hospital; home accounts for 22.6% of deaths.<sup>8</sup> Early identification and appropriate timely care planning could therefore assist in more efficient utilisation of scarce health resources and a more enhanced quality of life in the end stage coupled with a dignified death. To date, there are only two published studies which have tried to determine the prevalence of palliative care need in acute care hospitals the South African context. A prospective point-prevalence study, using a contextualised Gold Standards Predictive tool, conducted in 2011 of 10 hospitals in the Cape Town Metro found a 16.6% prevalence of palliative care need amongst hospital in-patients.<sup>11</sup> A second study, retrospectively reviewing mortality data from a tertiary hospital general medicine service in the Western Cape, determined mortality to be 11% at 3-months post discharge and 42% at 12-months post discharge.<sup>12</sup>

To expand and build a more comprehensive evidence base for the prevalence of palliative care need in South Africa, a more extensive study was undertaken. This study sought to ascertain the one year mortality after hospital admission, and this was used as a proxy indicator for potential palliative care need of patients across all acute care hospitals in the Western Cape Province of South Africa..

## **PARTICIPANTS AND METHODS**

### **Participants and setting**

Health services in South Africa are provided by a mixture of public and private providers and institutions. Of an estimated 56,5 million people (2017) in South Africa, 84% of people are dependent on government funded health services. While it is estimated that South Africa spends 8.5% of its gross domestic product (GDP) on healthcare, a stark public-private divide is reflected in the fact that only 4.1% of the GDP is spent on the majority of people utilising public healthcare, while 4.4% is spent on 16% of the population accessing private healthcare.<sup>13</sup> Alongside financial and human resource constraints in the public sector, care delivery is influenced by the high burden of disease and the low socio-economic status of the majority of patients.<sup>14</sup>

In the Western Cape Province of South Africa, 75% of the 5.8 million population utilise public health services. The province has 34 district hospitals with limited specialist services; 16 regional with some 24 hour specialist services and 3 tertiary/quaternary referral health facilities (a total of 9,802 inpatient hospital beds) delivering, based on severity of need, different levels of adult and child inpatient and outpatient care, emergency as well as psychiatric, rehabilitative and obstetric services.<sup>15</sup> Dedicated oncology inpatient services are only present at the tertiary/quaternary hospitals.

For this study, 46 government hospitals in the Western Cape Province were sampled including 31 district level hospitals, 5 dedicated tuberculosis hospitals, 4 psychiatric hospitals and 2 tertiary/quaternary hospitals.

### **Data Sources**

Patients seeking inpatient and outpatient services at health facilities in the Western Cape Province are assigned with a unique patient identification number (UPIN). This number is used to record all encounters across the different levels of care. The Western Cape Provincial Data Centre collects and links all electronic health data, including mortality data from both electronic and death certification sources. Each UPIN was assigned a unique study-specific identification number.

### **Objective of this study:**

To determine the proportion of patients who die within one year from their date of admission to hospital in public hospitals in South Africa.

### **Study Design**

A retrospective incident cohort study was conducted of all patients admitted to 46 acute-care hospitals in the Western Cape Province during a randomly selected two-week period from 15 March – 29 March 2012. The 2012 year was selected as it had the most completed mortality data and was accessed via the Provincial Health Data Centre, at the Western Cape Department of Health.

The inclusion criterion were patients at least 18-years or older on admission. Only the first admission during the time frame was included. All obstetric admissions were

excluded. The final cohort consisted of 10,761 patients. Variables extracted from the dataset included: age, sex, date of admission, date of discharge, the admitting department/speciality and date of death.

Data management and statistical analysis was conducted with Stata version 13.1, StataCorp, Texas, USA. Percentages in the results and tables have been formatted to one decimal place. Descriptive statistics were used to summarise patient data namely frequency and percentage for categorical data and median with interquartile range (IQR) for continuous data. Ethics approval was granted by the University of Cape Town's Faculty of Health Human Research Ethics Committee (HREC number 778/2016). Permission for data extraction was obtained from the Western Cape Department of Health data centre on 18 November 2016.

## **RESULTS**

A total of 10 761 patients met the study inclusion criteria during the two-week study period. There were more women (54.1%) than men (45.9%). The median age was 44 (IQR 31–60) years and the majority of patients (74.9%) were under the age of 60 years (*Table 1*).

There were 1570 deaths (14.6%) within a year of date of admission. Four hundred patients (25.5%) died during the index admission while 1170 of the deaths occurred after discharge (74.5% of all deaths). Overall, 25.9% of the deaths occurred during the first 7-days (n=406), 45.8% during the first 30-days (n=719), 68.3% by 90-days (n=1072) and 83.7% during the first 180-days (n=1314). Mortality rose with age (*Figure 1*) and as expected, was almost six times higher in patients aged 80 years and over compared with those who were under 30 years old (34.7% vs 6.3%) at one year post admission.

Most were admitted to district hospitals (5 795, 53.8%), followed by tertiary/quaternary hospitals (2 757, 25.6%) and then regional hospitals (1 945, 18.1%). Mortality did not differ significantly between the different categories of hospitals (District 14.7%, Regional 13.2%, Tertiary 15.7%). Specialist psychiatric hospitals admitted 171 during the study period and 5 patients died (2.9%) in one-year post

admission. Specialist tuberculosis hospitals had the highest mortality; of 93 admissions 27 patients died (29.9%) within one-year of admission.

Approximately half of patients, (5576, 51.8%) were admitted to medical specialities (internal medicine and oncology) while (4765, 44.2%) were admitted to surgical specialities (general surgery, orthopaedics and gynaecology). Of all admissions to the medical specialities, (1130, 20.7%) patients died within one-year of admission; oncology admissions had a higher mortality rate of 50.8%. Mortality was lower for patients admitted to surgical specialities (9.2% for general surgery and 5.3% for orthopaedic surgery). Gynaecological mortality was only 2.7% one year after admission.

## **DISCUSSION:**

### **i) Main findings:**

We established that 14.6% of all patients over the age of 18 years, admitted to medical and surgical beds in public hospitals in the Western Cape Province of South Africa, die within one year of hospital admission. 1 in 5 of patients admitted to medical wards and almost 1 in 10 patients admitted to surgical beds will die within the next year. The greater percentage of deaths in patients admitted to medical beds is likely a reflection of the natural burden of disease in South Africa, with death predominantly due to non-communicable diseases (ischemic heart disease, stroke, diabetes) and communicable diseases (HIV and tuberculosis).<sup>16</sup> In addition, although not formally assessed here, admission to surgical beds are more likely elective in nature whereas most medical admissions are due to acute deterioration. Although the numbers were small, patients admitted to specialised oncology beds, and those admitted to specialised tuberculosis hospitals had very high one year mortalities of 50.8% and 29.9% respectively. Overall the largest number of deaths are at district level hospitals and hospitals with general specialist services only, a reflection that the greatest number of beds are available there as mortality rates between levels of hospitals were similar. Given that a larger number of patients in their final year of life are in the medical wards, this suggest that the biggest need for palliative services would be in these wards at all hospital levels.

ii) what this study adds:

Some other studies across the world, exclusively in high income countries, have assessed 12 month mortality after admission with mortality rate of 11.6% (Ontario Province, Canada, and 14.5% (New Zealand), to 22%, 22.4% and > 25% (Denmark, Scotland, and a subset of patients > age 65 in Chicago, USA)<sup>17-21</sup>. Median age of admissions in these countries are however higher than in this South African cohort; all studies also show a strong correlation with mortality and age. This is the first study using record linkage data in an African context.

iii) Strengths and limitations of this study:

This paper has several strengths: it is the first study in Africa using data linkage and a unique patient identification number to link hospital admission data with mortality records. The study population is thus novel, with a young age of admission reflecting the demographic transition of non-communicable diseases seen in low and middle income countries, as well as a higher HIV and tuberculosis burden of disease. It is not clear how applicable these findings are to other provinces in South Africa and other low and middle income countries because the Western Cape has a lower burden of HIV-disease and better access to health care than other areas in South Africa.<sup>22</sup> This study is also limited in that data was only available for patients who died within the Western Cape; patients who moved to another Province would not have been captured. As such however it still reflects a “minimum” estimate. Given the incomplete ICD-10 coding for admission and on death certification, we were unable to estimate how many deaths were unrelated to the initial hospital admission, for example a death due to an unnatural cause; which may have biased findings towards an overestimate. In addition, using mortality data is only a surrogate for the number of patients in the last year of their life, and does not directly speak to actual palliative care need, which should be provided alongside curative care and earlier on the disease course as required.

## **Conclusion:**

At least 1 in 7 patients admitted to public hospitals in the Western Cape will die within the next year. Admission to hospital thus provides an important opportunity to identify such patients and initiate discussions around end of life care, advanced care

planning and palliative care, if not already begun. Most need would be in the medical specialities as the largest proportion of patients who are in their final year of life are in these wards.

(word count: 2196)

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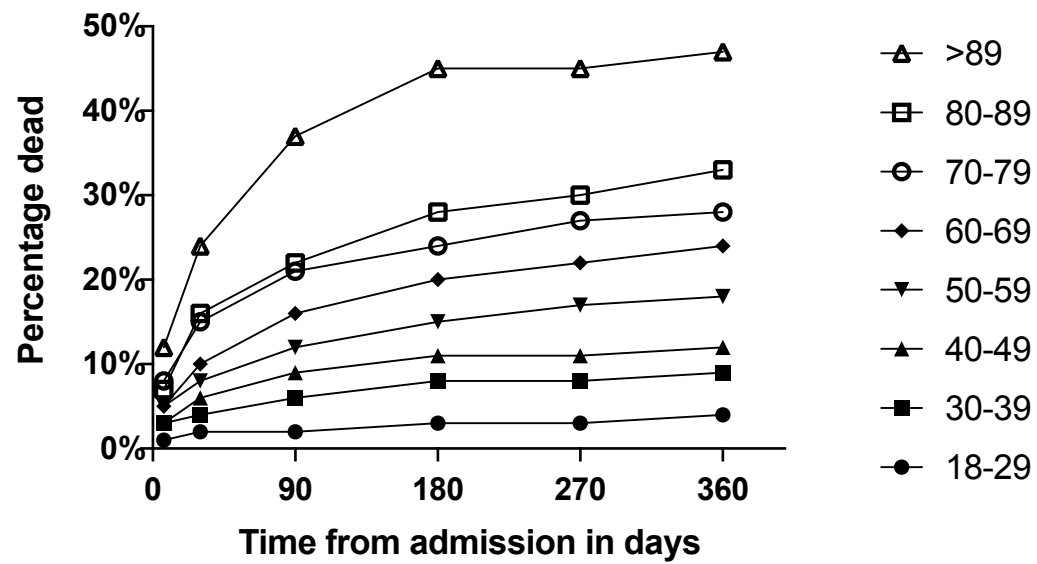
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**Table 1. Characteristics of the patient cohort and mortality rates**

	All admissions		Deaths within in one year		Alive after one year	
	n,	(%)	n,	(% of deaths)	n,	(% of alive)
<b>Total</b>	10761	(100.0)	1570	(100)	9191	(100.0)
<b>Gender</b>						
<i>Men</i>	4944	(45.9)	774	(49.3)	4170	(45.4)
<i>Women</i>	5817	(54.1)	796	(50.7)	5021	(54.6)
<b>Age (years)</b>						
<b>Median</b>	<b>44</b>		<b>57,5</b>		<b>42</b>	
18 - 29	2358	(21.9)	94	(6.0)	2264	(24.6)
30 - 39	2033	(18.9)	183	(11.7)	1850	(20.1)
40 - 49	1925	(17.9)	236	(15.0)	1689	(18.4)
50 - 59	1745	(16.2)	321	(20.4)	1424	(15.5)
60 - 69	1355	(12.6)	328	(20.9)	1027	(11.2)
70 - 89	907	(8.4)	256	(16.3)	651	(7.1)
80 - 89	387	(3.6)	128	(8.2)	259	(2.8)
≥ 90	51	(0.5)	24	(1.5)	27	(0.3)
<b>Specialties</b>						
<i>Medicine</i>	5458	(50.7)	1130	(72.0)	4328	(47.1)
<i>Surgery</i>	3393	(31.5)	312	(19.9)	3081	(33.5)
<i>Gynaecology</i>	729	(6.8)	20	(1.3)	709	(7.7)
<i>Orthopaedics</i>	643	(6.0)	34	(2.2)	609	(6.6)
<i>Psychiatry</i>	354	(3.3)	10	(0.6)	344	(3.7)
<i>Oncology</i>	118	(1.1)	60	(3.8)	58	(0.6)
<i>Other</i>	66	(0.6)	4	(0.3)	62	(0.7)
<b>Hospital type</b>						
<i>District</i>	5795	(53.8)	850	(54.2)	3196	(34.8)
<i>Tertiary/quaternary</i>	2757	(25.6)	432	(27.5)	2345	(25.5)
<i>Regional</i>	1945	(18.1)	256	(16.3)	1689	(18.4)
<i>Specialised psychiatry</i>	171	(1.6)	5	(0.3)	166	(1.8)
<i>Specialised TB</i>	93	(0.9)	27	(1.7)	66	(0.7)

Figure 1 : Cumulative deaths as a % of census admissions by age



**Declarations:**

**Authorship:** Petro Frankenfeld and Peter Raubenheimer designed and led the study. Petro Frankenfeld, Peter Raubenheimer and Lindi van Niekerk designed and wrote the study protocol.

Nicki Tiffin extracted the data set from Western Cape Department of Health data centre. Petro Frankenfeld, Peter Raubenheimer, Kathryn Manning and Nicki Tiffin analysed and interpreted data. Petro Frankenfeld wrote the first draft of the report and all authors reviewed and approved the final version.

**Funding:** This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

**Conflicts of interest:** We declare no competing interests.

**Research Ethics and patient consent:** The study was approved by the University of Cape Town – Groote Schuur Hospital Human Research Ethics Committee (HREC 778/2016).

Patient consent was not needed as data was extracted from routinely collected data entered into the Department of Health data base.

**Data management and sharing:** The corresponding author may be contacted regarding access to data.

## **Appendix**

Ethics approval:



**UNIVERSITY OF CAPE TOWN**  
**Faculty of Health Sciences**  
**Human Research Ethics Committee**



Room E53-46 Old Main Building  
Groote Schuur Hospital  
Observatory 7925  
Telephone [021] 406 6626  
Email: [shuretta.thomas@uct.ac.za](mailto:shuretta.thomas@uct.ac.za)  
Website: [www.health.uct.ac.za/fhs/research/humanethics/forms](http://www.health.uct.ac.za/fhs/research/humanethics/forms)

4 November 2016

**HREC REF: 778/2016**

**Prof P Raubenheimer**  
Internal Medicine  
J-Floor, OMB

Dear Prof Raubenheimer

**PROJECT TITLE: A RETROSPECTIVE COHORT STUDY OF MORTALITY AFTER HOSPITAL ADMISSION AS A PREDICTOR OF PALLIATIVE CARE NEEDS OF HOSPITALISED PATIENTS IN THE WESTERN CAPE, SOUTH AFRICA (Master's candidate-Dr P Frankenfeld)**

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

**Approval is granted for one year until the 30<sup>th</sup> November 2017.**

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period. (Forms can be found on our website: [www.health.uct.ac.za/fhs/research/humanethics/forms](http://www.health.uct.ac.za/fhs/research/humanethics/forms))

**Please quote the HREC REF in all your correspondence.**

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate Institutional approval before the research may occur.

***The HREC acknowledge that the student Dr Petronella Frankenfeld will also be involved in this study.***

Yours sincerely

signature removed

**PROFESSOR M BLOCKMAN**  
**CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE**  
Federal Wide Assurance Number: FWA00001637.  
Institutional Review Board (IRB) number: IRB00001938

HREC 778/2016





### Form FHS011: Study deviation

HREC office use only (FWA00001637; IRB00001938)		
This serves as acknowledgement of a protocol deviation as described below.		
Chairperson of the HREC signature	signature removed	Date 22/8/2019

#### Principal Investigator to complete the following:

##### 1. Protocol information

Date (when submitting this form)	20/08/2019
HREC REF Number	778/2016
Project Title	A retrospective cohort study of mortality after hospital admission as a predictor of palliative care needs of hospitalised patients in the western cape, South Africa
Protocol number (if applicable)	
Principal Investigator	Prof P. Raubenheimer - supervisor (Master's Candidate –Dr P. Frankenfeld)
Department / Office Internal Mail Address	peter.raubenheimer@uct.ac.za

##### 2. Protocol deviation description

Please describe the deviation below, including the reason why the deviation occurred.
Study not completed during the year of Ethics approval, Require extension of Ethics approval

##### 3. Follow-up actions

3.1 Please describe any follow-up action(s) taken or planned as a result of this deviation e.g. DSMB reporting, report to sponsor, informing participants.
None, only write up completion to be done, data collection and analysis is complete
3.2 Please describe what action(s) have or will be taken to prevent similar deviations in future.
Completion of study

##### 4. Principal Investigator's acknowledgement of responsibility





UNIVERSITY OF CAPE TOWN  
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

FACULTY OF HEALTH SCIENCES  
Human Research Ethics Committee



This signature indicates the PI has reviewed the deviation, taken appropriate follow-up action and implement or plans to implement preventative steps where possible.

Signature of PI	signature removed	Date	20/08/2019
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FACULTY OF HEALTH SCIENCES  
Human Research Ethics Committee



### FHS016: Annual Progress Report / Renewal

<b>HREC office use only (FWA00001637; IRB00001938)</b>			
<b>This serves as notification of annual approval, including any documentation described below.</b>			
<input checked="" type="checkbox"/> Approved	Annual progress report	Approved until/next renewal date	30.06.2020
<input type="checkbox"/> Not approved	See attached comments		
Signature Chairperson of the HREC		signature removed	Date Signed 22/8/19

Comments to PI from the HREC
<i>put into the deviation document</i>

**Principal Investigator to complete the following:**

#### 1. Protocol information

Date (when submitting this form)	20/08/2019		
HREC REF Number	778/2016	Current Ethics Approval was granted until	30/11/2017
Protocol title	A Retrospective cohort study of mortality after hospital admission as a predictor of palliative care needs of hospitalised patients in the western cape, South Africa.		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?		<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	
If yes, could you please provide the HREC Ref's for all sub-studies? Note: A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	Prof P. Raubenheimer – supervisor (masters candidate – Dr P. Frankenfeld)		



Department / Office Internal Mail Address	
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1.1 Does this protocol receive US Federal funding?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
1.2 If the study receives US Federal Funding, does the annual report require full committee approval?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<p>Note: Any annual approvals for <b>Full Committee</b> review MUST be submitted on the monthly HREC submission dates.</p> <p>(Please send electronic copy for full committee review to <a href="mailto:hrec-enquiries@uct.ac.za">hrec-enquiries@uct.ac.za</a>)</p>		
<b>If yes in 1.2 please complete section 1.3 below for invoicing purposes</b>		
1.3 Annual Approval for <b>full committee</b> review	- R 3450 (inclusive of vat)	
For invoicing purposes, please provide:		
Sponsor's name		
Contact person		
Address		
Telephone number		
Email Address		

## 2. List of documentation for approval

Protocol  
FHS 011  
FHS016  
FHS 019

## 3. Protocol status (tick ✓)

<input type="checkbox"/>	Open to enrolment
<input checked="" type="checkbox"/>	Closed to enrolment (tick ✓)
<input type="checkbox"/>	Research-related activities are ongoing
<input type="checkbox"/>	Research-related activities are complete, long-term follow-up only
<input type="checkbox"/>	Research-related activities are complete, data analysis only
<input type="checkbox"/>	Main study is complete but sub-study research-related activities are ongoing
<input type="checkbox"/>	Study is closed → Please submit a Study Closure Form (FHS010)

## 4. Enrolment

Number of participants enrolled to date	
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21 February 2019

Page 2 of 5

FHS016

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Number of participants enrolled, since last HREC Progress report (continuing review)	
Additional number of participants still required	

### 5. Refusals

Total number of refusals (participants invited to join the study, but refused to take part)	N/A
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### 6. Cumulative summary of participants

Total number of participants who provided consent	
Number of participants determined to be ineligible (i.e. after screening)	
Number of participants currently active on the study	
Number of participants completed study (without events leading to withdrawal)	
Number of participants withdrawn at participants' request (i.e. changed their mind)	
Number of participants withdrawn by PI due to toxicity or adverse events	
Number of participants withdrawn by PI for other reasons (e.g. pregnancy, poor compliance)	
Number of participants lost to follow-up. Please comment below on reasons for loss of follow-up.	
Number of participants no longer taking part for reasons not listed above. Please provide reasons below:	

### 7. Progress of study

Please provide a brief summary of the research to date including the overall progress and the progress since the last annual report as well as any relevant comments/issues you would like to report to the HREC:

Data extraction and analysis has been completed, no further analysis is required to complete the study.

Paper near completion.

### 8. Protocol violations and exceptions (tick ✓ all that apply)

<input checked="" type="checkbox"/>	No prior violations or exceptions have occurred since the original approval
-------------------------------------	---



<input type="checkbox"/>	Prior violations or exceptions have been reported since the last review and have already been acknowledged or approved
<input type="checkbox"/>	Unreported minor violations that have occurred since the last review, as well as significant deviations not yet reported, are attached for review

**9. Amendments (tick ✓ all that apply)**

<input checked="" type="checkbox"/>	No prior amendments have been made since the original approval
<input type="checkbox"/>	Prior amendments have been reported since the last review and have already been approved
<input type="checkbox"/>	New protocol changes/ amendments are requested as part of this continuing review (See note below)

Note: If new protocol changes are being requested in this review, please complete an amendment form (FHS006).

Specific changes in the amended protocol and consent/assent forms must be **bolded**, *italicised* or tracked and all changes must include a rationale.

**10. Adverse events**

10.1 Please provide below or attach a narrative summary of serious adverse events and/ or unanticipated problems since the last progress report. Please indicate changes made to the protocol and informed consent document(s) as a result (if not already reported to the HREC). Please comment on whether causality to any study procedure or intervention could be established.

Not applicable

10.2 Have participants received appropriate treatment/ follow-up/ referral when indicated (e.g. in the case of abnormal or incidental clinical findings, distress or anxiety)?

<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input checked="" type="checkbox"/> Not applicable
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If yes, please describe:

**11. Summary of Monitoring and Audit Activities (tick ✓)**

11.1 Was this study monitored or audited by an external agency (e.g. SAHPRA, FDA)?

<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input checked="" type="checkbox"/> Not applicable
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11.2 Did a Data and Safety Monitoring Board publish a report?

<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input checked="" type="checkbox"/> Not applicable
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11.3 If yes, please identify the agency and attach a summary of the findings.

Agency Name		Report attached	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable
		DSMB report attached	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable



11.4 Has there been any agency, institutional or other inquiry into non-compliance in this study, or any finding of non-compliance concerning a member of the research team?	
<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
If yes, please explain:	

## 12. Level of risk (tick ✓)

12.1 In light of your experience of this research, please indicate whether the level of risk to participants has:	
<input type="checkbox"/> Increased	
<input type="checkbox"/> Decreased	
<input checked="" type="checkbox"/> Shown no change	
If there has been a change, please explain:	

12.2 Please provide a narrative summary of recent relevant literature that may have a bearing on the level of risk.

## 13. Statement of conflict of interest

Has there been any change in the conflict of interest status of this protocol since the original approval? (tick ✓)	
<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
If yes, please explain and if necessary, attach a revised conflict of interest statement (Section #7 in the New Protocol Application Form FHS013):	

## 14. Signature

My signature certifies that the above is complete and correct.			
Signature of PI	signature removed	Date	20/08/2019